

CarersACT



2023-2024 ACT BUDGET SUBMISSION

April 2023

About Carers ACT:

Carers ACT is the leading body for carers in the ACT. We work to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We also work to ensure that caring is acknowledged and recognised as a shared responsibility of family, community and Government.

Our purpose is to support, connect and empower carers to maintain their caring role and personal wellbeing. The Carers Recognition Act 2021 recognises the value of carers and the care relationship and defines carers in the following way:

“A person is in a care relationship with another person if the first person (the carer) provides care to the other person for 1 or more of the following reasons:

- (a) the other person has a disability;
- (b) the other person has a mental disorder or mental illness;
- (c) the other person has an ongoing medical condition;
- (d) the other person is aged and frail;
- (e) the other person is a child or young person, and the carer is a kinship carer or a foster carer for the child or young person.”

Carers include family members, friends, relatives, siblings or neighbours.

In the ACT more than 50,000 people provide care. Carers provide an important role in the family and in the broader community, supporting the quality of life of the person they care for. A carer’s role can include help with daily living activities such as housework, transport, health care, shopping and meals, reading and writing, emotional and mental support and personal care.

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Introduction

Carers ACT acknowledges the ACT Government commitment to carers through the provision of funding for the *ACT Carer Strategy* emanating from the last ACT Budget. We are pleased to be working in a number of domains aiming to maximise the wellbeing benefits to carers. We recognise the Government has now fulfilled the majority of commitments to carers under the Parliamentary and Governing Agreement for the 10th Legislative Assembly.

Our Budget submission for 2023-24 highlights the need to ensure Budget decisions across all Directorates closely align with the principles of the *Carers Recognition Act 2021 (ACT)* ('the CRA'). As a vulnerable group recognised in the ACT Wellbeing Strategy, carers continue to experience low levels of general health, high levels of psychological distress, and social isolation. The most recent *Carer Wellbeing Survey* has revealed concerning yet unsurprising findings regarding the impact of caring on the overall wellbeing of carers.¹ According to the survey, carers are three times more likely to experience regular feelings of loneliness, with 39.4% often or always feeling lonely compared to 10.3% of the general Australian population.² Additionally, 48.1% of Australian carers, including those in the ACT, reported moderate to high levels of psychological distress.³ Almost half (48.6%) of all carers reported fair or poor health.⁴ The survey results highlight that carers are twice as likely to have low wellbeing compared to the average Australian adult, with 55.2% reporting low wellbeing compared to only 25.4% of the broader population.⁵

We remain concerned about the continued poor levels of wellbeing that carers experience, and our requests for Budget considerations focus on identified gaps expressed through active engagement and consultation. These include:

- Neurodiverse support services
- Palliative care
- Financial support for Government Strategies, including the ACT Disability Strategy and the ACT Disability Health Strategy.

Principle Priority

Our Budget submission prioritises the continued implementation of the CRA in Budgetary commitments so that recognition, engagement, and support for carers are present in all domains of the community. Carer wellbeing continues to be a major concern, with low levels of general health, high levels of psychological distress and social isolation being recorded.⁶ As a vulnerable group recognised within the ACT *Wellbeing*

¹ Carers Australia, "Caring for Others and Yourself: The 2022 Carer Wellbeing Survey," (Canberra: University of Canberra, 2022), [CARING FOR YOURSELF AND OTHERS \(carersaustralia.com.au\)](https://carersaustralia.com.au).

² Ibid, 16.

³ Ibid, 8.

⁴ Ibid, 9.

⁵ Ibid, 6.

⁶ Ibid.

Framework, positive impact across all domains of wellbeing should remain a matter of priority across the breadth of ACT's investment projects. We believe the ACT Government should be funding the incorporation of this legislation to such a degree that it provides 'best practice' leadership and demonstrates effective implementation of legislation that will improve the wellbeing of Canberrans. It is important that the Government recognises the impact of caring on carers and takes steps to address their needs. This budget we are not asking for a range of specific investments, rather we are asking for the inclusion of a carer focus in activities and outcomes across all Budget initiatives. This is the only way to ensure implementation of the CRA and improve the health and wellbeing of carers and through this the community.

Recommendations

Neurodiversity

Carers ACT recommends that the Government invest in initiatives that support neurodiverse individuals and their carers. In the context of autism alone, NDIS data finds that prevalence has increased substantially over the years. As of December 2020, there were around 137,000 participants on the autism spectrum, including around 80,000 children aged under 13 years.⁷ As of September 2022, 191,251 (34%) of the 554,917 active NDIS participants have a primary disability of autism, making it the most common disability for NDIS participants.⁸ Carers have told us that current service provision in the ACT does not meet this growing need. Likewise, it is essential when addressing this need, that the Government consider specialised spaces where diagnostic complexity and comorbidities (such as mental health) have produced significant gaps in service delivery within the ACT.

Support for neurodiverse individuals is not solely the domain of the NDIS. Many individuals are not eligible for supports through the scheme and often where they are these are not adequate. There is a strong need for health and early intervention services but also a need for community education that supports inclusion, resourcing to support policy decisions on inclusive education, adjustments to community events to ensure access by all and further consideration of environments controlled by the ACT Government to ensure access by people with sensory sensitivities.

Moreover, carers have expressed frustrations over the lack of respite options available for care recipients with neurodiversity, especially for young children (primary school age). Respite is an essential support service that promotes carer wellbeing by facilitating a much-needed break from caring responsibilities.⁹ It helps prevent

⁷ Australian Government, National Disability Insurance Agency (NDIA), "Consultation paper: Interventions for children on the autism spectrum," publication March 2021 (accessed April 2023), 5, <https://www.ndis.gov.au/media/3014/download?attachment>.

⁸ Australian Government, NDIA, "Explore Data Tool," March 2023 (accessed April 2023), [Explore data | NDIS](#).

⁹ See generally, David Evans, "Exploring the Concept of Respite," *Journal of Advanced Nursing* 69, no. 8 (2013), 1909, <https://doi-org/10.1111/jan.12044>; Yun-Hee Jeon, Henry Brodaty, Colleen O'Neill, and Jon Chesterson "'Give Me a Break'- Respite Care for Older Carers of Mentally Ill Persons," *Scandinavian Journal of Caring Sciences* 20, no. 4 (2006), 428, <https://doi-org/10.1111/j.1471-6712.2006.00423.x>.

carer burnout, stress, and relationship breakdown.¹⁰ For more information on the wellbeing impacts of respite please see the 2023-24 Budget Submission by Mental Health Carers Voice.

Palliative Care

We recommend that the Budget include funding to improve the supply of palliative care services and reduce service gaps that result in increasing caring responsibilities on carers. Care planners within Carers ACT have noted an increasing demand for palliative care services among Canberrans. Due to resource shortages, the quality of current service provision has also been flagged as an issue impacting carer wellbeing. We suggest that future services align closely with the *National Palliative Care Standards 5th Edition*, particularly Standard 3 (Caring for Carers) and Standard 4 (Providing Care).¹¹

Carers ACT acknowledges that there are significant challenges carers face in palliative care settings, and it is essential that the Government invests in initiatives that provide appropriate support and care for carers in such circumstances. We look forward to working closely together in the service design work for the 12-bed acute integrated palliative care ward at the Canberra Hospital that was committed to by the Government. We anticipate that the upcoming Budget will likewise address service delivery gaps in palliative care in the interim.

We note that Voluntary Assisted Dying does not replace palliative care and should not be seen as a solution to address the rising need for palliative care services. We support the availability of Voluntary Assisted Dying but urge that there is resourcing provided to specifically support carers through and beyond the death journey. We hope to see funding in the Budget to provide carer counselling, coaching and practical supports during the process for applying for and administering Voluntary Assisted dying and beyond. It should not be anticipated that this need can be incorporated into existing services and programs.

Funding Support for ACT Government Strategies

Carers ACT recommends funding support for ACT Government Strategies that will have a positive impact on the wellbeing of carers. This includes the;

- ACT Disability Strategy,
- ACT Disability Health Strategy,
- ACT Play Space Strategy,
- and ACT Women's Plan.

The success of these strategies intersects with positive outcomes for carers. They are critical to ensuring that carers receive appropriate support and recognition across all wellbeing domains, include 'Access and Connectivity', 'Health', and 'Time'. We urge the Government to commit to investing in these strategies and to

¹⁰ Ibid.




¹¹ Palliative Care Australia, *National Palliative Care Standards 5th edn*, (Canberra: PCA), [PalliativeCare-National-Standards-2018_Nov-web.pdf](#).

prioritise the wellbeing of carers in all associated policies and initiatives. The Budget should also consider providing funding and support for any additional strategies that aim to improve the wellbeing of carers, operating under the principle priority that these strategies align with the CRA.

Recommendation

Carers ACT urges the Government to take immediate action in the upcoming Budget to address the gaps and service deficiencies in the areas of neurodiversity and palliative care and provide funding packages that support the initiatives of key ACT Government Strategies. We anticipate a Budget that will incorporate the principles of the CRA across all proposed funding packages.

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